



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
Administration on Children, Youth and Families
Family and Youth Services Bureau

FYSB UPDATE

Modeling Partnership: The FYSB and ADD Demonstration Projects for Serving Youth With Developmental Disabilities

Serving all young people facing difficult life circumstances long has been the mission of local youth service agencies funded by the Family and Youth Services Bureau (FYSB). These agencies operate from the perspective that we must provide an array of services that help young people address all their needs and goals. Yet in the past, youth service agencies often have not been able to meet the needs of youth with developmental disabilities. Most youth agencies were not equipped to assess or respond to the special needs of these young people, many of whose developmental disabilities had previously gone undiagnosed by schools or other social systems.

FYSB and the Administration on Developmental Disabilities (ADD) recognized this gap in service delivery for young people with developmental disabilities and began discussing how

to address it in 1993. They subsequently signed a Memorandum of Understanding agreeing to further explore issues related to enhancing services to this population and appointed the Task Force on Serving Youth With Developmental Disabilities to help them. The Task Force comprised representatives from each agency's network: youth service professionals (FYSB) and disabilities advocates (the ADD). Task Force members identified barriers that made services to youth with developmental disabilities less accessible, particularly the lack of collaboration between the disabilities and youth service fields.

The Task Force, therefore, strongly urged FYSB and the ADD to fund demonstration projects that would create teams of youth service agencies and disabilities advocates. The youth service agencies would

The FYSB/ADD Demonstration Projects

During the past several years, there has been increasing awareness of the number of youth with developmental disabilities who are living in at-risk circumstances. The first step in assisting these young people is to translate that awareness into strategies that help communities meet their needs. One method for creating effective approaches is to test practical interventions in a range of settings through demonstration projects.

Two agencies within the Administration for Children and Families, U.S. Department of Health and Human Services, are doing exactly that. In 1995, the Family and Youth Services Bureau (FYSB) and the Administration on Developmental Disabilities (ADD) began jointly funding three demon-

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bring extensive experience in working with young people and their families, especially during periods of crisis. The disabilities advocates would offer experience in assessing and developing plans for working with youth with disabilities. Together, they would forge new partnerships that might serve as models of collaboration for other communities.

FYSB and the ADD moved quickly to announce the availability of demonstration funding to partnerships of youth service agencies and disabilities advocates in fiscal year (FY) 1995. They subsequently awarded funding to the following three teams:

- Boston, Massachusetts: "Bridges to Inclusion Project"

Bridge Over Troubled Waters, Inc. (FYSB grantee)
Institute for Community Inclusion (ADD grantee)

- Cincinnati, Ohio: "Priority One Independent Living Project"

Lighthouse Youth Services, Inc. (FYSB grantee)
University Affiliated Cincinnati Center for Developmental Disorders (ADD grantee)

- Omaha, Nebraska: "Wrap-Around Services for Youth With Disabilities in Shelter Care Programs"

Youth Emergency Services, Inc. (FYSB grantee)
Meyer Rehabilitation Institute (ADD grantee)

Those teams first came together at a forum hosted by FYSB and the ADD shortly after the grant awards were made. They discussed their project designs and explored ways that the projects could share information throughout the demonstration period.

Together, the FYSB and ADD grantees have forged new partnerships that might serve as models of collaboration for other communities.

In August 1997, representatives of the three projects met again to share their experiences in working collaboratively, the lessons they had learned, and their expectations for the future. Common themes emerged during their presentations, with each team reporting the following:

- Identification of a higher proportion of youth with developmental disabilities than expected
- The importance of collaboration between youth service agencies and disabilities advocates to develop and

sustain improved strategies for supporting youth with developmental disabilities

- The need for, and benefits of, having disabilities advocates provide ongoing training to youth service agency staff on identifying and working with young people with disabilities

Youth With Developmental Disabilities

Even though the project teams comprised agencies that recognized the need for enhanced services for youth with developmental disabilities, they were surprised at the number of youth with disabilities that they began identifying through the demonstrations. The Nebraska team, for example, projected that approximately 20 percent of the youth assessed by the project would be identified as having a disability. The actual number was almost double that projection; of the first 230 youth served by the project, almost 40 percent had a disability.

In addition, the Boston project team conducted a survey of youth service providers that found the following:

- 94 percent of the youth service agencies that responded stated that they served youth with an identified disability
- 93 percent of the responding agencies stated that they

served youth with suspected but unidentified disabilities

Youth agencies responding to the survey said that they witnessed behaviors that might be indications of unidentified disabilities. These included difficulties with personal relationships, aggressive behavior, mood swings, hyperactivity, and problems handling instructions from multiple staff members.

Ironically, these behaviors, which might be symptoms of a physical challenge, may have led to youth receiving services in the first place.

Generally, the responding agencies also reported that their staff believed that they lacked the experience and skills to adequately deal with young people with developmental disabilities. Of the respondents, 66 percent reported that they were insufficiently prepared to effectively provide services to individuals with complex disabilities. Moreover, the crisis oriented structure and limited funding of most youth service agencies did not provide staff the time or resources necessary to individualize services for youth with disabilities.

The Boston project team also conducted a survey of disabilities advocates. The results indicated that, generally, this professional group was unaware that a problem of unidentified

or untreated disabilities among runaway and homeless youth existed. While 42 percent of respondents reported that they were vaguely aware of this issue, 40 percent said that it had not been raised as a major concern within their organization. Only 34 percent of the respondents reported that they

Collaboration requires an acknowledged need, a commitment to creating positive advances in the area of collaborative focus, and respect between the partners.

had a working relationship with emergency shelters for runaway and homeless youth.

This lack of awareness was brought into sharp focus in several instances in which youth service professionals and disabilities advocates operating in the same geographic area realized that they knew very little about each other's organizations. Yet both sets of survey respondents indicated a willingness to work together.

Model Partnerships

What typically makes collaborations work is an acknowledged

need, a commitment to creating positive advances in the area of collaborative focus, and respect between the collaborative partners. Early in the FYSB/ADD demonstration projects, the teams acknowledged the critical role that each partner organization would play. With time, the organizations developed heightened respect for the expertise that their partners brought to those roles.

As the projects were implemented, the project teams made several observations about the natural course that the collaborations should take. Each project team agreed that the youth agency should serve as the primary point of contact with young people. The youth agencies were known within the communities and had outreach teams and networks of referral sources.

It naturally followed that youth service agency staff would require assistance in addressing the issues facing youth with developmental disabilities. Youth agency staff needed training about the nature of these disabilities, methods for identifying young people with these conditions, and strategies for assisting them. The disabilities advocate partners brought considerable expertise in these areas; most also managed strong training programs.

In working together, each partner developed increasing respect for the other and, therefore, the collaboration. The disabilities advocate partners valued the youth agencies' visibility, connections, and approach to supporting young people and their families. The youth service agency partners appreciated both the disabilities advocates' technical expertise and their commitment to helping young people and their families.

With the partnerships strengthened by this shared respect and commitment to youth, the teams moved ahead with their plans. These included training staff, improving systems and tools for identifying and assessing youth with developmental disabilities, developing comprehensive and targeted approaches to meeting the needs of youth with developmental disabilities, and creating opportunities for youth to achieve their potential.

Training of Staff

While each project chose to train staff on slightly different topics and through unique processes, the three projects' areas of focus for the trainings overlapped. All three included training components on the various types of disabilities and how to identify them.

The Boston project team, for example, began by conducting

a needs assessment of Bridge Over Troubled Waters staff to determine what they knew about working with youth with developmental disabilities and what they needed to learn. Through this needs assessment, the project team evaluated the Bridge staff's basic understanding of such concepts as mental retardation, learning disability, and attention deficit disorder.

The disabilities advocate partners valued the youth agencies' visibility, connections, and approach to supporting young people and their families.

The Institute for Community Inclusion (ICI) then developed a training curriculum based on the Bridge staff's needs and the resiliency model, a construct shared by both partner agencies. Through an initial training, staff were taught to concentrate on young people's positive attributes rather than on the disability. This approach helps young people build a positive sense of self, thereby encouraging them to take advantage of what the program has to offer. Using this technique also helps

staff understand each young person in the context of the adolescent life stage rather than attribute all behaviors and attitudes to the disability.

The Boston team's initial training concluded with a wrap-up session in which Bridge staff discussed techniques they had applied to their work with youth with disabilities, what worked, and which strategies they would continue to use.

The senior team members, however, found that Bridge staff continued to encounter situations for which they felt unprepared. Their solution was to initiate forums, similar to case management sessions, in which staff could discuss with each other their work with youth with disabilities. At the forums, senior project staff provide guidance regarding individual situations and then schedule followup meetings to check on each young person's progress.

The Boston project also extended its connections with individuals and agencies with expertise in working with youth with disabilities, and therefore potential trainers, through an Advisory Committee. The committee included representatives of such agencies as the Massachusetts Rehabilitation Commission, Department of Mental Retardation, Department of Mental Health, Boston school

system, and Department of Public Health. Bridge staff began a brown-bag lunch series, inviting speakers from these organizations to make presentations to youth service staff on how to obtain access to each agency's services for young people.

The Nebraska team's training program comprises preservice and inservice training and ongoing program and individual case consultation. The Meyer Rehabilitation Institute (MRI) provides the Youth Emergency Services (YES), Inc., staff with 24 hours of preservice training within the first 30–60 days of employment. The preservice training provides information on disabilities, behavior management, and strategies for working with youth with disabilities, with an emphasis on positive motivation. The format is not didactic; staff role-play situations using their new skills. The MRI also collaborates with senior YES staff to offer about 18 hours of ongoing inservice training. The inservice training component focuses on family therapy from a short-term intervention perspective.

The Cincinnati project team realized that many youth with developmental disabilities already were obtaining access to Lighthouse Youth Services' programs through referrals from other agencies or Lighthouse

outreach activities. The goal of their training, therefore, was to improve staff's ability to identify youth with disabilities and ensure their referral for further assessment by the University Affiliated Cincinnati Center for Developmental Disorders (UACCDD).

The youth service agency partners appreciated both the disabilities advocates' technical expertise and their commitment to helping young people and their families.

Each of the projects, in fact, focused their early efforts on equipping youth service professionals with the tools to conduct on-site assessments and make appropriate referrals of young people to their developmental disabilities partner agency for further evaluation.

Identification and Assessment of Youth With Developmental Disabilities

The project teams all established a two-stage assessment process. In stage 1, the youth service professional conducts an initial assessment of the young person as part of the intake

process. If the results of that initial assessment seem to indicate a potential developmental disability, the young person is referred to the disabilities advocacy partner.

In stage 2, the disabilities advocate in each partnership administers a series of more comprehensive tests. These are designed to provide more indepth information regarding the nature of a young person's disability or combination of disabilities.

Key to the assessment process was selecting an assessment tool that is both accurate and simple for youth service agency personnel to administer. The Cincinnati project team chose the K-Bit. This brief intelligence assessment tool gives an indication of IQ and supplies administrators with information useful in making referrals for services.

The UACCDD trained the Lighthouse staff in using the K-Bit to conduct primary diagnosis of mild retardation and borderline intellectual functioning. The UACCDD also provided briefings on detecting learning disabilities, attention deficit disorder, hyperactivity, and language disorders, and on dealing with epilepsy and seizure disorders, spina bifida, cerebral palsy, and Tourette's Syndrome.

The Lighthouse intake process includes a number of simple

triggers to alert staff that further assessment using the K-Bit might be warranted. Lighthouse staff, for example, might ask youth to complete a form; if they are unable to do so, staff flag their records. If young people were receiving special education services prior to entering the program, their records also are flagged.

Youth whose records are flagged then are assessed using the K-Bit and, if indicated, referred for further assessment for disabilities and mental health issues by the UACDD. The Cincinnati project team chose to conduct mental health assessments because mental health issues often can affect a young person's performance in ways that resemble a developmental disability. Differentiating between the two is critical to designing the young person's service plan. Moreover, project staff increasingly became aware that a developmental disability may not be the primary issue facing a young person who is dealing with mental health or addiction issues.

The Nebraska team developed an extensive set of assessments for use in the preliminary screening process. These assessments, which cover several categories of disabilities, include the following: cognitive, for developmental disabilities or

mental retardation; academic achievement, for learning disabilities; emotional or depression; substance abuse or dependency; and suicide ideation. MRI staff then conduct assessments of youth referred through the YES preliminary screening process.

As each of the project teams were training staff and implementing their assessment

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process, they used those experiences to begin developing a more comprehensive approach to serving young people identified as having developmental disabilities.

Development of Comprehensive and Targeted Services

While all young people are unique, they share common issues related to being an adolescent in today's culture. Their well-being also is influenced by families, schools, employers, their economic status, and the broader community. A successful treatment program, therefore,

must be both comprehensive and targeted to each young person's special circumstances and needs.

The Nebraska team's project name, the Wrap-Around Services for Youth With Disabilities in Shelter Care Program, was intended to reflect that approach to working with young people and their families. Wrap-around services are designed to address young people's range of needs in the most accessible and comprehensive way possible.

YES operates two facilities, one for boys and one for girls. Both shelters provide "family style" living for runaway and homeless youth and use positive reinforcement and reward systems for behavior management. The primary case managers develop individual program plans for each young person, and youth maintain contact with their families through "home passes." The project's social skills program emphasizes how to accept criticism, follow instructions, take "no" for an answer, and build problem solving skills.

MRI services "wrap around" the YES services, making them more comprehensive. MRI services include psychological counseling, educational disability assessments, and family

therapy. The family counseling component of the Nebraska project is considered one of its most important, since reuniting young people with their families is a goal of all FYSB-funded runaway and homeless youth programs. Engaging families early in the process is critical to making that possible.

The MRI's family therapy services focus on communication, especially learning to listen to one another. Youth generally participate in several individual sessions to enable them to share information they might be reluctant to provide in front of family members. The family then joins the young person for another four to six sessions.

As the family focuses on supporting the young person, the MRI and YES support the family. Drawing on the young person's needs-and-strengths assessment and a home assessment, the agencies jointly develop a family service plan that includes referrals to other relevant services. Case management, family mediation, and in-home family support are frequently provided by social work student case managers. Each case manager provides services, such as assisting young people in finding jobs and helping their families to take advantage of available services. In cases in which there is no family (or foster family) to

work with, a staffperson from the MRI is assigned as a wrap-around specialist to coordinate services for the young person.

In Cincinnati, Lighthouse provides self-sufficiency training and independent living opportunities for young people with developmental disabilities in several out-of-home placement settings. These include scattered-site, agency-rented apart-

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ments in which young people live by themselves or with a roommate, and a staff-supervised shared home in which three or four youth live. The agency also matches each young person with developmental disabilities with a youth mentor who has successfully participated in Lighthouse services.

In addition, a UACCDD staffperson works with Lighthouse staff to explore the obstacles youth with disabilities and their families face and to develop services that support those youth and families. The

UACCDD also provides programmatic and client-focused consultations to Lighthouse staff.

As the demonstrations progressed, each of the project teams came to realize that while young people with developmental disabilities may need specialized services, they also need opportunities to develop a sense of self, build skills, establish a sense of purpose, and gain a sense of belonging. The project teams, therefore, all created activities for young people from a youth development perspective, which focuses on providing young people with services and opportunities that allow them to achieve their full potential.

Creation of Opportunities

Project staff came to believe that what mattered most was not offering services, but rather creating in youth an understanding that they have the right to a better life and the means to attain it. Often, this perspective must be established before youth can "buy in" to a program and make a real commitment to their future.

The Boston project staff sought to empower youth by inviting them to contribute to the project. One young person, for example, became an assistant trainer by volunteering to participate in the program's new assessment process and provide

feedback to staff about the procedure. This process both gave project staff valuable insight into the assessment process from a young person's perspective and provided the young person with a sense of purpose. That young person currently serves as the youth representative to the project's Advisory Committee.

Another Boston project activity is the "portfolio project," designed to build youth participants' self-esteem. Each young person is given a book with a page for each year of their life. They fill each page with positive experiences. When completed, the book provides positive reinforcement of each young person's life. In the back of each book, space is provided for such things as a résumé, birth certificate, and social security card to reinforce the notion that the book is to serve as a practical tool in everyday life. The book is not intended to be a project that is completed and then put away, but a constant reminder about what lends importance to a person's life.

Looking forward is, of course, of equal import to looking back. The Boston team, therefore, offers life skills training to youth with developmental disabilities, with a concentration on providing skills youth need to get a job. Staff conduct training on job-seeking and networking skills and help youth

establish long-term employment goals.

Equipping youth with the skills and resources necessary to make the transition to self-sufficiency also was a primary goal of the Cincinnati project. The project modified the approach used in the Lighthouse Transitional Living Program to teach young people with developmental disabilities

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the skills they need to move toward independence.

The Nebraska project also focuses on ensuring that youth have every option open to them. That might mean focusing on helping youth develop self-sufficiency skills, concentrating on strengthening the family, or both. The staff emphasize that many of the project activities take place in the home because the ultimate objective is to facilitate the successful return of young people to their families, when appropriate.

Most important, the combined expertise of the youth agencies

and disabilities advocates increased the likelihood that youth with developmental disabilities would be ready to take advantage of the opportunities available through the community. Through enhanced assessments, increased staff awareness and skills, and new activities designed specifically for youth with special challenges, the demonstration projects are modeling effective methods of applying the youth development approach to serving young people. They do so by helping youth deal with the challenges of a disability while focusing on their strengths and interests.

The Future of the Demonstrations

As the FYSB/ADD demonstrations move through their final year of operation, the teams are applying their lessons to new projects. They also are establishing systems for sharing information with other agencies interested in improving access to services for youth with developmental disabilities.

The Nebraska project staff plan to open their training programs to other shelter supervisors. Later, the partner agencies may begin charging a nominal fee for the training courses. Those fees will be used to support the continuation of the Wrap-Around Services Program.

The Cincinnati team produced a set of resources for parents of young people with disabilities and for the youth themselves. The agency also revised its life skills training materials for all the agency's programs to take into account the special needs of youth with developmental disabilities. Moreover, the project team is offering its training on developmental disabilities to participants in the Lighthouse foster parents network.

In addition, during the course of the project, Lighthouse brought together a separate working group to examine the issues young people with special health needs face as they make the transition to adulthood. The agency subsequently received a 4-year grant to implement the findings of that working group. These include having the agency work with schools to ensure that youth receive necessary services, develop a collaborative forum in which professionals can share information, and serve as an information center for families, young people, and the agencies that work with them. The new project, "Transitions: Healthy and Ready to Work," will enable Lighthouse and the UACCDD to continue to apply the lessons learned through the FYSB-funded demonstration.

The Boston project is reaching out to share its experience with

other agencies interested in replicating its approach. Two members of the project team conducted a workshop at the National Network for Youth's 1998 Annual Symposium and plan to host other trainings. The ICI also began reformulating its training initiatives for the ADD; with support from other agencies, it will look at transition issues for youth across the age spectrum.

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For more information on these demonstration projects, please contact the grantees:

- "Bridges to Inclusion Project"

Bridge Over Troubled
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617/423-9575

Contact: Barbara Whelan or
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Institute for Community
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Children's Hospital
300 Longwood Avenue
Boston, MA 02115
617/355-6506

Contact: Bill Kiernan or
Cecilia Gandolfo

- "Priority One Independent Living Project"

Lighthouse Youth Services,
Inc.

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Contact: Bob Mecum or
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Contact: Tom Gannon or
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- "Wrap-Around Services for Youth With Disabilities in Shelter Care Programs"

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Contact: Kathy Henrichs

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About the FYSB/ADD
Demonstration Projects
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stration projects to improve services to youth with developmental disabilities. To be considered for funding, applicants were required to form a team consisting of a FYSB-funded youth agency and a disabilities advocate from the ADD grantee network.

Funding demonstration projects was but one of the recommendations of the FYSB/ADD Task Force on Serving Youth With Developmental Disabilities, convened in 1994 following the signing of an interagency Memorandum of Understanding. Since their inception, the demonstration projects have worked to address other Task Force recommendations. These include improving the exchange of information and collaboration between youth service providers and disabilities advocates, identifying model approaches for working with young people with developmental disabilities, and disseminating information on these approaches.

In August 1997, FYSB and the ADD brought together representatives from the three project teams to share their findings from the second year of funding. This update shares those preliminary lessons.

Resources for Serving Youth With Disabilities

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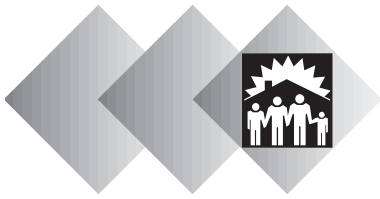
Integrating Young Children With Disabilities Into Community Programs: Ecological Perspectives on Research and Implementation. Editors: C.A. Peck, S.L. Odom, and D.D. Bricker. 1993. Available from Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624; 410/337-8539.

Living Your Own Life: A Handbook for Teenagers by Young People and Adults With Chronic Illness or Disabilities. Authors: N. Roberts et al. 1993. Available from Parent Advocacy Coalition for Education Rights (PACER) Center, Inc., 4826 Chicago Avenue South, Minneapolis, MN 55417; 612/827-2966.

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